

The Katie Beckett Story

by Katie Beckett

There seems to be a lot of misconceptions about my life. I do not live the glamorous, exciting life that many people may believe I lead. I did not get a birthday present from the Reagan's this year. I do not have a standing invitation at the White House. I do not hang out with the Kennedy family. I am not good friends with Chelsea Clinton; the only Chelsea I know is my stepsister.

I do not unusually have fancy, expensive dinners with politicians when I go to Washington. I do not live the glamorous life when I go there. A typical visit would have me running through O'Hare airport in Chicago to make my connection flight at the other end of the airport. The gate always has to be the furthest from the one I land at. While on the plane I will be listening to my favorite music and the attendant will tell me to turn off the CD player in the middle of my favorite song. Once we land we'll wait to leave until after all the other passengers leave because of all the medical equipment we have to haul. We'll wait forever to get a taxi and find out we won't, make the dinner because our plane was late.

The hotel rooms do not usually have three televisions or TV's in the bathroom. Exhausted, my mother and I will order room service and sleep. The day on Capitol Hill will involve short meetings with Congressmen's (Congresspersons) assistants rarely the Congressmen themselves, and their offices will be in different buildings that are far away from each other. This is why I always remember to bring comfortable shoes and wear layers because you will get hot from all that walking.

After a day of walking we again return to the hotel room to go to sleep and go home if we do not go on a plane the same day of the meetings. Do I enjoy these trips? I do because I know that I am making a difference and usually I get to see other advocates that I respect and admire.

There are some things that are true: I do have mothers and some fathers who come up to me crying because they are on the Katie Beckett waiver* or they have been helped by Family Voices and I do get invitations to speak or appear from politicians and highly respected groups like the Robert Wood Johnson Foundation, Children's Hospital of Boston and the Princess Diana Foundation. These are pretty heady things for a 22 year old, but like Kid Rock says in my favorite song, "Only God Knows Why", "...somehow I know there is more to life than this". What I mean by that is that I know there is more to my life than all the attention that I receive. The most important thing I want people to know is that I am really just a girl who loves concerts, basketball and wrestling. I am just a girl who got very, very lucky.

"Till next time, take care of yourself and each other."

* Medicaid Waivers are state-run programs that use federal and state funds to pay for health care for people with certain health conditions. Without Medicaid Waivers, thousands of children with special health care needs would either

go without health care (because of their health condition and/or financial situation), or would be institutionalized in order to qualify for Medicaid. Medicaid Waivers permit states to use flexibility to design publicly financed health care systems outside of certain federal Medicaid statutory and regulatory requirements. Each state has different Waivers with different eligibility requirements or services. Two Medicaid statutes are currently waived: 1915 and 1115.

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